

# Should mortality data for the elderly be collected routinely in emergencies? The practical challenges of age-disaggregated surveillance systems

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Data on the elderly are rarely collected in humanitarian emergencies. During a refugee crisis in South Sudan, Médecins Sans Frontières developed a prospective mortality surveillance system collecting data for those aged  $\geq 50$  years and found that the elderly were dying at five times the rate of those aged 5–49 years. Practical and ethical issues arose. Were reported ages accurate? Since no baseline exists, what does the mortality rate mean? Should programmatic changes be made without evidence that these would reduce the elderly mortality rate? We outline issues to be addressed to enable informed decisions on response to elderly populations in emergency settings.

**Keywords:** Humanitarian, Elderly, Refugee, Emergency, Mortality, MSF

## Background

Minimum standards for humanitarian assistance require collection of age-disaggregated data.<sup>1</sup> However, in practice, data on the elderly are rarely collected and humanitarian programmes are not tailored to meet the specific needs of this age group.<sup>2</sup> The medical humanitarian agency, Médecins Sans Frontières (MSF) has observed wide variation in its own programmatic responses to the elderly in emergency settings.<sup>3</sup> When resources are limited and far outweighed by needs, the response to a complex humanitarian emergency requires difficult choices. Since the mid-1990s, guidelines such as MSF's Refugee Health and the Sphere project have defined priorities, quality standards and indicators for emergency responses.<sup>1,4</sup> Are these standards fit for the humanitarian situations of today and the future? The world population is ageing rapidly and, increasingly, those involved in humanitarian assistance will need to be able to respond to older age groups more effectively.<sup>2</sup> There is much work to be done on developing a framework to determine how agencies decide who to prioritise in emergency settings and much could be learned from ethics-based approaches common in donor transplantation and emergency medicine.<sup>5</sup> However, in this paper, we start from the premise that responding to the needs of the elderly is a moral and ethical imperative for humanitarian agencies. Here we discuss some of the practical issues that need to be addressed based on our experience in a refugee crisis in South Sudan.

## South Sudan refugee crisis

In July 2012, over 100 000 people were displaced from Blue Nile state in Sudan and arrived at three camps in Maban County, South Sudan: Doro (41 000), Jamam (30 000) and Batil (35 000).<sup>6</sup> As part of the MSF response in Jamam, a standard prospective mortality surveillance system recorded population, numbers of structures, births and deaths disaggregated into two age groups:  $<5$  and  $\geq 5$  years. Data were collected by trained local outreach workers. Cause of death and age at death were reported by household members. A field epidemiologist noted a high proportion of deaths in those aged over 50 years. In response, the surveillance system was adapted to collect data on three age groups:  $<5$ , 5–49 and  $\geq 50$  years. Crude and age-disaggregated mortality were calculated. It was found that the elderly, comprising 10.5% of the population, were dying at over five times the rate of those aged 5–49 years (3.45 vs 0.61 per 10 000 per day, respectively).<sup>7</sup> Although there are limited data for rural Africa, age-specific mortality rates in those  $\geq 50$  years have been noted to be over ten times higher than in those aged 5–49 years in the rural African settings of Kilifi, Kenya, and Rufiji, Tanzania.<sup>8</sup> However, a direct comparison with our data is difficult. In the stable settings of Kenya and Tanzania the  $\geq 50$  years mortality rate averaged less than 1 death per 10 000 per day.<sup>8</sup> In addition, the  $\geq 50$  years mortality rate in Jamam may have been influenced by delay in collection of data for this group and by the possibility that the most vulnerable elderly

people died before reaching the camp or in the early emergency response.

## Implementation and challenges of prospective age-disaggregated mortality surveillance

Adaptation of the surveillance system in Jamam firstly involved discussions with the MSF teams of local outreach workers about its feasibility. Forms were redesigned and intensive training (two sessions) and on-the-job supervision were provided. All forms were checked daily, reported deaths were cross-checked and daily random spot checks of the teams were conducted. Although the system was intensive and included exhaustive household visiting, the outreach workers did not report that it greatly increased workload.

Several issues arose during data collection. Were reported ages accurate? Was there a bias towards over-estimation by the population of the age of someone who had died? Since no baseline exists, what does the  $\geq 50$  year mortality rate in Jamam mean? And should programmatic changes be made based on this one rate without evidence that such changes would reduce the elderly mortality rate?

## Staff attitudes

Of concern, there was a negative response during initial discussions of results among several international MSF staff members. Comments included suggestions that MSF will need Zimmer frames and bed pans, through to assumptions that increased mortality in older people is most likely due to chronic diseases. These comments suggest that humanitarian workers may have been trained to think that current humanitarian emergency responses are adequate, and that there is no need to question whether we can or should try to improve our approach. By contrast, in an MSF emergency response in Haiti, health workers were more ready to include the elderly and perceived them as vulnerable, and some efforts were made to target the humanitarian response to their needs.<sup>3</sup>

## Conclusions

Collecting age-disaggregated mortality data in emergency settings is feasible as we have demonstrated in South Sudan. However, more needs to be done in determining which focussed programmatic activities for the elderly will improve their well being, including understanding humanitarian aid worker and societal attitudes towards the elderly. Box 1 outlines operational research questions and issues that need to be addressed to enable informed decisions to be made on response to elderly populations in emergency settings. The recent launch of the open-access INDEPTH archives containing prospective age-disaggregated mortality data is a welcome step towards addressing some of these issues.<sup>9</sup>

In addition to the collection of age-related mortality data, there is the need to improve age disaggregation of several indicators and to consider developing elderly-specific indicators. However, this raises ethical questions about the decision to invest time and resources in extra data collection during emergencies without evidence that adjustments in programme implementation will lead to improved outcomes. In assessing answers

### Box 1. Practical challenges and operational research questions in collecting mortality and morbidity data for the elderly

- Define appropriate age grouping (e.g.  $\geq 50$  or  $\geq 60$  years): what is 'old' and should it be established separately in each country/region? And how should this be done?
- Valid comparison data are needed from non-emergency settings in low and middle-income countries to establish a baseline expected mortality rate for the elderly.
- In communities that may not keep records or prioritise date of birth, how accurate are ages obtained by asking household members for the age of the deceased?
- Assess societal attitudes to value of elderly people during emergency and societal norms around choice of provision of scarce resources.
- Thresholds for action: how much variance is there in expected mortality rates between settings? Is the variance enough to merit variable thresholds for different settings? What are the ethical implications raised if so?
- Are standard morbidity indicators, which have traditionally been focused on infectious diseases, appropriate for elderly populations likely at higher risk of chronic/non-communicable diseases? If not, then there is a need to define appropriate morbidity indicators for the elderly (that may differ by region) that could include:
  - infectious diseases
  - key chronic diseases with high risk of significant morbidity and mortality: cardiovascular disease including severe hypertension, diabetes, chronic respiratory disease
  - nutrition indicators.
- Develop appropriate indicators of access to services, including water, sanitation and health care.
- Ensure training of humanitarian workers includes sensitisation on recognising the needs and potential vulnerability of the elderly population.

to these questions, it is important to assess how different cultures value older populations and how differing cultural norms could influence attitudes to who to prioritise with limited medical care during emergencies. Adapting medical ethical frameworks developed for scarcity of resources in western settings may be helpful in informing difficult programme management choices in the midst of complex humanitarian emergencies.

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